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ABSTRACT

Puerto Rican males have been ranked among the top five groups in the world suffering from oral cancer. Since the typical victim is an elderly male, from the Puerto Rican rural and lower socioeconomic areas, who is chronically unemployed or underemployed, lives alone, and is a heavy drinker or smoker, social support network creation was considered a viable intervention. A social support intervention strategy was developed which involved four phases: (1) identification of high and low risk friends of a patient and existing support sources; (2) contact between the community link and potential cases; (3) diagnosis and treatment, with the patient being accompanied by the community link; and (4) follow-up and final evaluation. A pilot study was conducted with 21 potential patients to evaluate the effectiveness of the first three phases. The study concluded that community support systems could facilitate identification and follow-up of persons with oral cancer and could identify social support networks operating in communities. Despite evidence of the effectiveness of the intervention, the proposal was not supported by federal authorities. Possible explanations for this lack of support are considered. (NB)

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Community Support Systems: One Response to Non-Compliance

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The main purpose of this paper is the description of a community intervention that was carried out in Puerto Rico to increase compliance of oral cancer patients to early diagnosis and follow-up (Negrón, 1984) through the creation of community support networks.

Oral Cancer in Puerto Rico: Its Victims

During the past decades Puerto Rican males have been ranked among the top five groups in the world suffering of cancer of the tongue, mouth, and pharinx (SEER,1981). The typical victim is an elderly male, from the Puerto Rican rural and lower socio-economic areas, who is chronically unemployed or underemployed, lives alone, and is a heavy drinker or smoker. He drinks in groups which are alienated and peripheral in relation to the community, thus making them impervious to conventional detection systems (Fraumeni,1975;Martínez, 1969; Negrón,1984 ; Schottenfeld & Fraumeni, 1982). Due to this situation, social support network creation was considered a viable option.

Need for a Social Support System

As most of you know the literature has established a positive relationship between health and social support. Social support has been

associated with recovery and coping with a serious illness and (b) individuals with stronger social support networks have higher motivation to adhere to medical regiments and also have more clarity of the consequences of non-compliance (Di Matteo and Hays, 1981).

Data has also been provided regarding the characteristics of social support networks that affect their effectiveness. These are discussed in the unedited paper but will not be presented due to our time limitations.

Creation of a Community Support System for Oral Cancer Patients

The proposed intervention strategy was composed of four phases . The first phase Identification involves identifying both high risk and low risk friends or associates of a patient as well as other existing sources of support. All those that meet specific criteria are then recruited as community links. Their tasks include accompanying the previously identified person or patient to all diagnostic and treatment referrals, following-up his or her adherence to medical treatment if so prescribed and maintaining contact until the patient is recovered.

The second phase refers to the Contact between the community link and Potential Cases. Once identified, the community link makes an

appointment forthe patients' first diagnosis visit and assures his/her attendance. Thirdly there is Diagnosis and Treatment . Here the patient follows through his or her medical assessment, being accompanied at all times by the community link. If the patient does not receive a positive diagnosis, the community link discontinues contact. If the patient does receive a positive diagnosis the community link will be responsible for attendance to subsequent visits and compliance with the prescribed medical treatment.

The fourth phase consists of Follow-up and a Final Evaluation. Community links are responsible for follow-up until the patient is fully recovered, until his/her support is not needed, until the patient dismisses the community link or until a final evaluation interview.

This proposal was not been implemented in full but a pilot study was carried out in the summer of 1984 so as to evaluate the effectiveness of the first three phases. This was required by NIH, whose only expressed doubts at the time with the proposal concerned the effectiveness of the community intervention.

Pilot Study

The pilot study was initiated with twelve persons living in the northeastern region of the island. These were identified and interviewed. They were asked to provide names of associates and of places where they most often met. The two associates that were selected for follow-up lived in two economically disadvantaged suburban communities.

Characteristics of Associates

The final group of associates that was identified consisted of 21 males whose ages ranged from their late thirties to their late sixties.Two (9.5%) had never worked, eleven (52.4%) were currently unemployed and 9 (42.9%) were employed.

Employment instability was a common characteristic among the unemployed as well as the employed. None had professional or vocational skills, twelve had left school before or at the sixth grade level and nine between the ninth and twelveth grade. The basic source of income of the unemployed were food stamps. Their nutritional habits were irregular, all were habitual drinkers, while most were also habitual smokers.

Of the 21 associates, four (4,19%) were married, three (3,14%)

were widowers, six (6,29%) were divorced and eight (8,38%) were single. Some had children but had lost contact with them.

A key characteristic observed among this high risk population was that they often sought individuals with similar habits. Other important characteristics included: economic hardship, poor hygiene and physical and mental health problems. Although they recognized their erratic behavior sometimes, thus showing capacity for self-assessment, this was countered by a deep sense of helplesness and impotence to overcome their problems .

Operation of the Community Support System

Differences were noted beween the support systems in the communities. In Community I (urban) the group met at different times mainly during the daytime while in Community II(rural) those unemployed spent the whole day together and those who worked met them at the bar after 3:00 PM. In this community the interviewer found a higher degree of group cohesion. Other members of the community also provided the men with support.

The members of the social support networks in both communities had almost constant contact day and night. The intensity and duration of the

contact was also very high. Thus, their network was extremely dense.

The impact of these characteristics seemed positive in terms of fostering concern and caring from sources of support and in terms of increasing reliability of pertinent information. However, they reinforced a very closed group which maintained most of its unity by the acceptance of behaviors which the community rejected and are harmful to their health. It also reinforced each man's sense of helplessness and lack of control over his circumstances . These latter characteristics fostered non-compliance to treatment.

Discussion

Aside from learning about the type of social support networks operating in the communities, the project concluded that community support systems could facilitate identification and follow-up of associates with oral cancer. Stemming from 2 initial associates, 21 potential patients were identified in only six weeks and clinical diagnosis was performed on most.

Critical Evaluation

After reviewing this experience we must think about the impact of this type of intervention on our communities and our society. We also want

to share some ideas on our explanation for the final lack of support from federal authorities to our proposal, despite evidence to the effectiveness of the intervention.

It is hard to oppose interventions which are designed to foster health. Efforts such as these facilitate the identification of community resources, fortify cohesion in neighborhoods and help organize and movilize self-help efforts. However, they also allow government to evade its responsibility for financing interventions, leaning instead on community resources and organization. In a way we foster the belief that government does not owe itself to social and human service, but instead should devote its efforts to other issues which include the development of private enterprise and military growth.

We believe this is precisely what explains our proposals' rejection. The proposal required that community links be payed for their work and for their daily expenses so as to follow-up of patients. This provided a new source of employment for aging, unemployed men. Finally it required the recognition of community organizing efforts as professional endeavors.. These were all conditions that demanded from the authorities a

commitment to the project, not only in terms of the promotion of health but in terms of the process by which it would be obtained. In our opinion the proposed process was not acceptable since it opened the doors to future demands on the part of the affected communities. In other words it fostered their empowerment. Thus we must face the reality of on the one hand creating interventions which fortify our communities, while helping government to avoid its responsibility toward the underserved of our society.

Lastly, this intervention presents a problem that all programs committed to the unempowered must face. Since this type of intervention cannot lead to radical social change , is it really possible to achieve changes that do not exclusively contribute to foster the integration of these groups into the established and unjust norms of our society? Do we have the right to alter their behavior patterns so as to improve their health according to our definitions of what their good health should be? Do we in this way foster submission before the medical profession and services with their many defects? On the other hand if we do not intervene, having the capacity to do so, do we free ourselves from our responsibility to marginal

populations? We do not wish to answer these questions. We wish only to present that that which at first glance seems to be an ideal project, with unquestionable goals, presents the continuous dilemmas which those of us which call ourselves social change agents must face.

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